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**Treatment Accessibility for Co-Infected IDUs in China: A Likelihood for HIV, an
Improbability for Hepatitis C**

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Submitted in partial fulfillment of the requirements for China: Language, Cultures and Ethnic

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Abstract:

In a country which provides free medicine and care for patients living with HIV/AIDS, China has not included a crucial piece of the problem in its health care scheme. In Yunnan Province alone, 77.7 % of intravenous drug users are co-infected with HIV and hepatitis C. While these patients can obtain treatment for HIV with ease, they cannot do so to treat their hepatitis C infection, a viral disease that leads to liver failure. Recent trends indicate that more co-infected patients are dying of HCV rather than HIV due to treatment inaccessibility. This study investigates the severity of HCV in China, the barriers to obtaining treatment, and what alternatives exist for patients infected by HCV. Over the course of one month, formal interviews were conducted with 18 intravenous drug users, two medical doctors specializing in infectious disease, and one Traditional Chinese Medicine doctor. The answers were analyzed to compare the experience of patients to the experiences of doctors and how this correlated with the shortfalls in HCV treatment distribution.

There are four findings which point to the underlying causes. First, there is a gap between what medical doctors assume to what patients experience. While doctors claimed that HCV treatment is highly successful, not a single IDU who was interviewed had successfully completed the regimen. Second, finances and stigma serve as the largest barriers to obtaining treatment. Third, in order to cope with these barriers, patients find emotional reprieve in community support and treatment alternatives in Traditional Chinese Medicine. Fourth, the solution requires changes from both the Chinese health care system and foreign pharmaceutical companies. The goal of this research is to raise awareness about the gaps in knowledge and efforts surrounding hepatitis C to create a sense of urgency to fill them. This study will assist nongovernmental organizations and public health entities in understanding the problem of HCV in China so that they can implement improved and sustainable solutions.

Topic Codes:

HIV/AIDS; Hepatitis C; Co-Infection; Public Health; Global Health; Intravenous Drug Users;

Health Care;Yunnan

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Introduction:

Chronic hepatitis C, an infection in the blood which is most notable for causing liver failure, plagues 130-150 million people in the world today (“Hepatitis C”, 2015). In recent years, its incidence has crept up faster than governments or public health entities can catch up with. Hepatitis C (HCV) first came to my attention in China because of its relation with HIV/AIDS. Both disease are transmitted via blood, both are chronic and harmful disease, and both can be treated. However the situation in China is unique. In a country which provides all 1.3 billion of its citizens universal health care, HIV treatment is free and easily accessible whereas hepatitis C treatment is not. Throughout my month long research period, I investigated coping methods and treatment options for people co-infected with HIV and HCV. In addition, I sought to understand patterns between people’s living environments and their behaviors in accordance with their HCV infection. I originally planned to focus on infection of HCV among HIV infected Intravenous Drug Users (IDU), however my aimed shifted to treatment barriers and alternatives instead. My hopes in conducting this research is to raise awareness about the lack of HCV treatment accessibility among people in China and internationally. This is the first step in lobbying for treatment in China which would cure the millions who are infected with Hepatitis C.

Background for Hepatitis C and HIV/AIDS

Yunnan province, located in southwest China, is particularly unique case. Located along the border of Myanmar, Laos and Vietnam, the province is subject to cross border interactions, including drug trade. “The Golden Triangle” is the nickname for the drug trade route that serves as the doorway between Yunnan and Southeast Asia. The Golden Triangle, “the world’s largest opium-based drug production and trafficking bases”, is the reason Yunnan has one of the highest number of drug users in China, and thus why it has the highest HIV/AIDS incidence (“Moving Towards”, 2009). The direct correlation between

IDU's and the HIV/AIDS epidemic is not coincidental. Nor is the increasing number of people with HCV. Acknowledging that one of the populations at risk of being infected with hepatitis C are those infected with HIV, according to the World Health Organization (WHO), Yunnan is an ideal case study to examine HIV and HCV co-infection.

As previously mentioned, the WHO recently reported that a staggering 130-150 million people in the world are infected with hepatitis C. However, it must be noted that this number does not account for those who are infected with HCV but have not been tested. Blood transmission is the main route in which HCV is transmitted. Injection drug users (IDU), female sex workers (FSW), men who have sex with other men (MSM), and mother to child transmission are the most common catalysts for HCV transmission. Upon infection, the incubation period lasts 2 – 24 weeks during which patients are asymptomatic. The next stage of HCV is acute illness where patients experience symptoms characteristic to hepatitis C, such as jaundice, fatigue and nausea. As the virus progresses, it develops into chronic HCV infection (“Viral Hepatitis”, 2015). It is during this stage where many die of chronic liver disease, cirrhosis and liver cancer. According to the WHO, about 500,000 people die a year of chronic hepatitis C related deaths (“Hepatitis C Factsheet”, 2015).

Human Immunodeficiency Virus (HIV) and hepatitis C overlap in many ways. For one, both diseases share the same transmission route. This explains why the prevalence of co-infection among intravenous drug users is particularly high. According to the WHO's HIV/AIDS Fact Sheet, the most recent statistics indicates that approximately 36.9 million people are infected with HIV globally, and 40% receive anti-retroviral therapy (ART). Last year alone, 1.2 million people died from HIV related deaths (2015). In addition, successful treatment for both HCV and HIV has been developed and released to both developed and developing countries. For the last 30 years, the global effort to eradicate HIV/AIDS has made a profound impact worldwide. The United Nations listed the “Eradication of HIV/AIDS” as one of the

eight Millennium Development Goals to achieve by 2015. HIV/AIDS is considered one of the “big three” global diseases to tackle, along with malaria and tuberculosis. Governments around the world are investing in their own international governmental organizations, like USAID, to support the cause. Thanks to the global fight against HIV/AIDS, the UN reported that the number of people newly infected with HIV per year has decreased 40% since 2000 (The Millennium Development Goals Report, 2015). The fight against HIV/AIDS serves as a model for the eradication of HCV and other major diseases worldwide.

Gaps in Efforts and Understanding

When contrasting the two diseases, the educational awareness surrounding HCV is not up to par with the ones made for HIV. The Aids prevention and treatment campaign swept China starting in the early 90’s and continues today. “The Four Frees and One Policy” program was implemented in 2005 to eradicate the HIV/AIDS epidemic in China. All patients with HIV are guaranteed free testing, free antiretroviral treatment, free medication for pregnant women infected with HIV, and free education to orphans living with HIV. The policy also grants economic assistance to families who have a family member suffering from HIV (“Moving Towards”, 2009). Furthermore, prevention efforts are being made throughout the country, especially in large cities. HIV/AIDS clinics which are scattered throughout major cities provide educational awareness services. Other educational advertisements can be seen in public places. For example, Kunming’s public busses show informational commercials on the dangers of HIV. However, measures such as these have yet to be achieved for other diseases, like hepatitis C.

Given the rising incidence of HCV worldwide and the scarce access to treatment, a movement with a similar magnitude of the global fight against HIV/AIDS is necessary. However, there are many gaps that must be filled in order to make this possible. One gap to note is the lack of knowledge about the severity of the disease and the number of people

infected. Pharmaceutical companies also must make treatment affordable and accessible worldwide. In addition to these gaps, it is important to understand the systematic and structural problems that prevent patients from receiving these medications so that sustainable solutions can be made. My goal in this research is to investigate the severity and treatment accessibility of people living with hepatitis C, using HIV as a comparison. In order to do so, I used the following questions as guidance for my research: How common is co-infection and how serious is the HCV problem in Yunnan? What are the socio-economic patterns that exist among patients? What treatments for HCV are available in China? What barriers exist for those who want to obtain treatment? How do patients cope with these barriers? What are the gaps which explain why problems exist?

Justification for Research

According to the Universal Declaration of Human Rights Article 25, access to health care is a right for “adequate” living (1948). Regardless of race, income level and any other social or economic status, all people deserve access to health care and treatment, especially for life threatening illnesses. Hepatitis C is no exception, which is why the World Health Organization has listed the medication on its Essential Drugs List (EDL). This list, which has been adopted by 136 countries, is a compilation of what the WHO deems as the most vitally needed drugs worldwide (2015). However, many pharmaceutical companies have undermined the purpose of the EDLs, like with the case of the most recent treatment developed for hepatitis C. Hepatitis C and HIV, two diseases that in the past and today have plagued millions, co-infect drug users via the same transmission route. Despite the similarities between the two disease and the sense of urgency to prevent transmission and treat patients, access to HIV treatment is free, but not for HCV. The goal of my research is to uncover the severity of the public health threat, the barriers to attaining treatment, and existing solutions in order to raise awareness about the issue and lobby for further action to

be taken. With this, I hope that NGOs and the Chinese government can work alongside one another to take action in making HCV treatment free and attainable for all people.

Methods:

Both HIV and HCV have been brought to the public health attention in China in recent years. Given the nation's rapid economic and social development within the last 40 years, globalization of disease has occurred as a result. The Chinese government has been faced with the challenge of keeping up with the rapid changes that are occurring in public health. Knowledgeable that there are shortfalls in how the country deals with these challenges, China is a case study worth researching. Yunnan province, as previously mentioned, is a unique case study because of its geographic location. It is the third leg of the Golden Triangle, the cross border drug trade between China, Burma, Laos and Vietnam. The drug trade makes Yunnan home to a large IDU population which is how I came to choose this vulnerable population. The high number of drug users correlates with the high prevalence of HIV and HCV. The province was described as "one of China's worst affected provinces in terms of HIV prevalence" ("Moving Towards", 2009). I chose to focus my studies primarily in Kunming, the largest city and capital of Yunnan based on size, population, and resources related to health. The other locations of my study were chosen to compare and contrast situations to Kunming.

Various methods of gathering information were used to conduct research on HIV/HCV co-infection, the primary one being interviews. I conducted formal interviews with 18 intravenous drug users, two western medicine doctors, and one Traditional Chinese Medicine Doctor. Twelve of interviews with IDUs were conducted at Sunshine Homeland Center in Kunming. Introduced to me by Yundi Organization, Sunshine Homeland Center was the best resource to interview IDUs because the services they provide attract drug users around the city. IDUs attend the clinic daily to take the government subsidized HIV treatment and receive education to prevent the spread of HIV and HCV. The individuals I interviewed were randomly selected by the Center's manager, Mr. Zhang, based on

attendance. They ranged in age, gender, and health statuses so that my data would represent the general IDU population. Some were infected with HIV only, some were infected with HCV only, and some were co-infected with both viruses. The following list is the name of the IDUs I interviewed at Sunshine Homeland November 10th and 11th: Wan Xiaowei, Zhou Mi, Zhang Bing, Lu Hong, Zhang Ming, Zhang Xiaorong, Yen Liwei, Luo Shaowen, GuoZhong, and Du Fang. Ma Yunfeng and Li Yen Li were interviewed at Yundi Office. Their answers are representative of IDUs' attitude surrounding their health and treatment accessibility.

The same applies for the six patients interviewed in Yuxi, Kunming's neighboring city. The names of the six are Yang Li Kun, Zhang Xiaomin, Zhou Hongchun, Liu Hong, Qi Shaojin, and Dai Yunchuan. Five patients were chosen randomly by Mr. Dai, Yuxi's Harm Reduction Network's program director, based on their attendance. Mr. Dai himself was interviewed as the managing director of the clinic for his experience and knowledge. Again thanks to Yundi organization, I was put in contact with Mr. Dai. This center provides methadone treatment for drug addiction, outreach, and free HIV testing. Yuxi, the second most populated city in Yunnan, was chosen as a case study to compare the socio-economic situations among civilians in Kunming and Yuxi. The city has a significantly high population of HIV infections due to the high number of drug use. Since the city is home to a tobacco industry which employs a large number of Yuxi civilians, many economically prosper off the industry, enough to fund their drug use. In recent years, the city has been a target for NGOs and government entities who seek to combat the HIV problem (Y. Dai, interview, November 20, 2015). These interviews provide a unique comparison to circumstances in Kunming.

The remaining interviews were conducted with specialists in his or her respected medical fields. I interviewed a medical doctor, Dr. Yang Jie, who specializes in hepatitis C

treatment in Kunming. The information she provided helped me understand treatment options in Kunming and patients' tendencies when taking treatment. It was also an opportunity to contrast the patient's outlook on the treatment to the doctor's. The interview was conducted at The Yunnan Infectious Disease Hospital in Kunming. As the city where most of my interviews were conducted, I wanted to ensure that the information provided by the patients and the doctors were as consistent as possible. The other interview was conducted with Dr. He, a medical doctor at the Public Health Clinical Center in Chengdu. I chose to do a comparative study on Chengdu because of its location. Sichuan is Yunnan's neighboring province to the north, and Chengdu is its capital. The purpose of this comparison was to see if the incidence of co-infection and attitude towards treatment differed in another major city in China. The final interview I conducted was with Dr. Zhao from the Traditional Chinese Medicine University and Clinic in Kunming. His specialization provided a comparative study to alternative HCV treatments.

The information gathered from interviews with drug users was analyzed based on patterns of their answers (interview questions for IDUs can be found in Appendix A). I broke up my interviews with drug users into three sessions. The questions asked in each session varied according to their circumstances, however many questions applied to all. For example, I asked different questions to people who had HIV and people who were co-infected, but for all I asked about their background, health status, etc. The question asked pertained to whether or not they had previous education about the disease before being diagnosed, their overall health status, and their attitude towards HCV treatment. These questions were intended to reveal if public health measures were sufficient enough for both prevention and treatment. Furthermore, their answers were meant to expose the connection between socio-economic situations and access to treatment. Interviews with medical doctors, on the other hand, were meant to contrast patient's attitude and accessibility towards

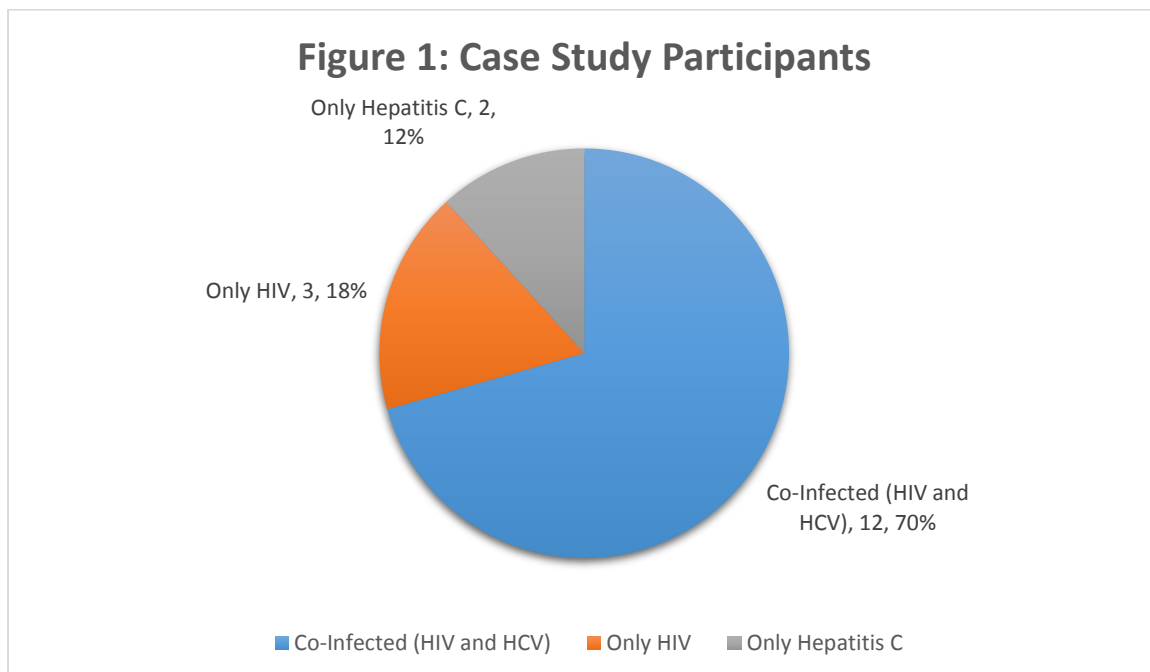
treatment to the administrator's experience with the intention of better understanding a patient's experience and exposing biases. This also helped in investigating the purpose and repercussions of the treatment from a professional medical perspective since many of the IDUs I interviewed were not knowledgeable of the treatments. I traveled to Chengdu, Sichuan to interview one of the medical doctors who specializes in HIV and HCV treatment in order to compare two large cities in China who have very different public health efforts and distribution of socio-economic factors. Finally, a Traditional Chinese Medicine doctor, Dr. Zhao, who specializes in a field which combines Western Medicine and TCM was interviewed. Given the number of IDUs I interviewed who resorted to TCM to supplement their health, I concluded it was worth investigating what alternatives existed to the difficult to obtain HCV medication.

Supplemental information, such as statistics, background on China's health care, and research on pharmaceutical companies, was gathered via electronic sources and print material. Print material was acquired thanks to the SIT library based in Yunnan Minzu University and Yundi Organization's reports. The reports were used to analyze the efforts and shortfalls of other studies and projects. Other textual sources and online resources related to background information, China's health care policy, HIV in China, and hepatitis C treatment controversy.

Throughout the course of my research, I encountered many barriers and limitations in which I had to overcome. For example, I was faced with the likelihoods that drug users I interviewed did not tell the truth. This occurred with one woman who said that she was not infected with HIV even though Yundi staff revealed to me later that she was in fact infected. In order to deal with this situation, I discounted a portion of her interview in my data analysis. In addition to potentially having untruthful interviewees, language barrier was another struggle to overcome. Translators, such as my colleague from Yundi, Liu Wen Jun, are necessary when conducting cross-language interviews.

Results:

After conducting interviews over a two week period with intravenous drug users, the results that I found coincided with my initial hypotheses. Out of all 18 individuals I interviewed, 100% of them were current IDU's or had previously used intravenous drugs then had quit. Twelve people out of 18 (67%) were co-infected with HIV and hepatitis C. I also interviewed three people living with HIV only and two people living with HCV only (see Figure 1). The interviewees were randomly selected based on their availability and attendance at their respected medical clinic; however, their educational levels were staggeringly similar. Only two of the individuals had completed a high school education. Twelve interviewees had a junior middle school education level, with one of the twelve people dropping out part way through. With one individual not disclosing their educational level, the remaining three had completed a primary school education.



I found that very few drug users had knowledge about HIV or HCV before they were diagnosed. For the individuals who are currently HIV positive, only two of them admitted to knowing fully about the disease when they began using intravenous drugs and before their diagnosis. The majority consisted of eight people who had limited to moderate knowledge of

HIV before their diagnosis, whereas seven had absolutely no knowledge about the disease. The remaining one is not applicable to the interview question. Out of the individuals who have been diagnosed with HCV, including co-infected patients, only one knew fully about the disease and four had limited to moderate knowledge. The remaining 10 (not including the three in which this question did not apply) had absolutely no knowledge about hepatitis C before their diagnosis. When applicable, one interview question inquired whether or not the person living with HCV would take a treatment recently developed by the United States that is less harmful and more affordable. The responses given are noteworthy. Discounting four individuals for which this question did not apply, only two people responded “no” due to their negative outlook on their health. Three eagerly responded “yes, absolutely.” However, the large majority of nine people hesitated because of financial concerns, answering yes only if it were free or significantly reduced in price. The results of my findings aid already existing discussion about HIV and HCV co-infection in China that I later discuss.

The Prevalence and Severity of Co-infection:

The cry for help is heard globally as the incidence of HCV rises. Around the world, an estimated 130-150 million people, 3% of the world’s population, is infected by the virus. China surpasses the global average with 3.2% of its population living with HCV, and it ranks as the third country in the world with the highest incidence behind Egypt (22%) and Pakistan (4.8%)(Ford et al, 2012).However, conflicting evidence from the Department of Pharmacology and Therapeutics at Liverpool University noted that China has the highest prevalence of HCV with 29,791,212 people infected with the virus (Hill and Khoo, 2013). Regardless of contradicting statistics, the numbers still remain concerning, as are global efforts to combat the disease. As inconsistent data proves, the global fight against HCV is not a coherent effort made globally.

Based on my interviews and data collection, HCV infection has become more severe, especially among vulnerable populations such as IDUs and HIV positive individuals in Yunnan. According to a recent study conducted by a team of researchers from the Yunnan Key Laboratory of Vaccine Research & Development on Severe Infection Diseases and various other groups, 15.6%-98.7% of IDUs in China tested positive for hepatitis C (the number ranges depending on geographic location). The team conducted a study on the prevalence of HCV genotypes in Yunnan, using the same reasoning for the province's geographic location along the drug trafficking border of Southeast Asia. In their research they reported that 77.7% of IDUs in Yunnan are HCV-positive. After taking blood samples of individuals throughout the province, they noted, "our results provided further information to support the assertion that this drug trafficking route has influenced the rate of HCV transmission and changes in genotypes among IDUs in Yunnan Province" (Zhang, 2013). While their research focused on the genotypes common in a specific region, they still noted the province's high prevalence rates of co-infection and HCV.

Based on interactions with individuals who are co-infected and people who work with them, their personal experiences point to the fact that co-infection is a growing problem. Zhang Xiaomin is a grassroots member of the Harm Reduction Network, a medical clinic located in Yuxi dedicated to providing methadone treatment for drug users and disease testing. Zhang himself is also an IDU and is co-infected with HIV and HCV. Given his experience working at the clinic and interactions among his peers, he estimated that 90% of the IDUs that attend the clinic are co-infected. Not only is the prevalence high, but he also noted with a solemn expression that in the last two years he has not heard of anyone who had died of HIV related causes, rather the cause of death is related to hepatitis C complications (interview, November 20, 2015). Dr. Yang who specializes in HIV and HCV treatment at Yunnan's Infectious Disease Hospital also echoed this concern. She noted that

in the past few years, the incidence of HCV co-infection has greatly increased, as has the number of people who die of HCV instead of HIV. The HIV virus can be easily stabilized, she commented, so people are living long and full lives (interview, November 25, 2015). However, this is not the case for those who are co-infected. Zhang Xiao Rong is 44 years old and is co-infected with HCV and HIV. In an interview conducted at Sunshine Medical Clinic she was asked whether HIV or HCV affected her life more. She responded that hepatitis C serves as a much bigger concern. She knows that HIV is treatable, but must face the fact that there is nothing she can do for her hepatitis C infection (interview, November 11, 2015). Many co-infected patients share this sentiment. Based on interviews and supplemental information, it is clear that the severity of hepatitis C, including its prevalence and death toll, will continue to grow unless measures are taken.

Social and Economic Determinants

In order to understand how the current circumstances came to be, one must take a look into the structural environments that many IDUs are subject to. Socio-economic situations play a strong role in determining one's health education and health outcomes. My results have found that there is a correlation between the educational level of the individuals I interviewed and their knowledge of HIV and/or HCV before diagnosis. Fifteen individuals I interviewed (83%) had a junior middle school education or less, making them more likely to have lower paying jobs and less economic opportunities. The United Nations and other major international organizations strongly argue that education is key to bringing people out of poverty and away from harmful activities. With that in mind, one can argue that there is a correlation with lack of education and the number of people who had little to no knowledge of the diseases prior to diagnosis. Based on my interviews, 93% of people did not know about HCV and 88% did not know about HIV before diagnosis. One can find the correlation with educational levels and likelihood of preventing and also treating the disease.

Since the goal of my project is to study HIV and HCV co-infection among intravenous drug users in Yunnan, Yuxi is an ideal location to do so. The city is located two hours away from Kunming by car and rivals Kunming's size and population. Cigarette production is the main industry the city financially thrives off of. As a result, those who gain off the industry have made a generous income, enough to pay for their drug use. In recent years, as my colleague Liu Wen Jun explained, there has been an increased incidence of people living with HIV and hepatitis C due to the influx of income. I interviewed drug users to determine how their lifestyles have influence their health. In addition, I sought to investigate what their attitude is towards taking HCV treatment. I wanted to determine if an improved economic situation influences people's decision on whether or not they want to take costly HCV treatment. However, what I found was not what I expected. The individuals I interviewed frequently attended the same medical clinic to take methadone treatment for drug addiction. They did not benefit from the tobacco industry, nor were they even employed to begin with. Out of the five IDUs I interviewed at the medical clinic, four were unemployed and the fifth was an employee of the center. One could argue that their economic and health situation were worse compared to those at Kunming's Sunshine Center. Many, including Liu Hong, had low spirits about the state of their health. When I inquired about his outlook about the future, he stated that he has no hope for his life as he held back tears (interview, November 20, 2015). The situation in Yuxi is far different from the one in Kunming, thus proving that no situation in China is the same and the solution cannot be one size fits all. Furthermore, the scope of the HCV problem in China must be looked at through the lens the socio-economic barriers that exist in order to make sustainable solutions. Understanding structural circumstances aids in understanding the root of the problem.

HCV Treatment in China

While affordability is a determinant to obtaining medication, there are existing treatments that are commonly used in China to treat hepatitis C. The regimen which doctors generally prescribe is a combination of interferon and ribavirin. Ribavirin is an antiviral medication that, when combined with interferon, stops the virus from spreading inside the body and thus prevents liver damage (“Ribavirin”, 2013). A patient has the option of either taking the long term regimen or the short term regimen. The long term interferon regimen, as explained by Dr. Yang, requires the patient to take an injection medicine at the clinic once a week while the short term regimen requires treatment at the clinic every two days. These injections cannot be administered by the patient, but requires the patient to come to the clinic for each injection. The regimens can last 24-48 weeks and the success rate differs for each individual (interview, November 26, 2015). In Chengdu, Dr. He proudly noted that the success rate for her patients who take the medication is 92% (interview, November 30, 2015). The regimen given to patients is simply protocol for the doctors who administrate it. However, the patients have much different experiences

There are many factors which threaten the success rate of patients who take the treatment, especially among vulnerable populations. One of which are the harsh side effects associated with the treatment. Dr. Yang mentioned that some patients experience flu like symptoms, fever, hair loss, and weight loss. Ribavirin causes the white blood cell count of an individual to decrease (interview, November 26, 2015). For those who have preexisting heart problems, it is extremely dangerous to take Ribavirin because it may cause anemia and heart attacks (“Ribavirin”, 2013). When asked if side effects deter patients from continuing the treatment, Dr. He shared that “few” give up on the treatment because they know prior to taking the medication that such side effects may occur. Those that stop the treatment before completion are those whose health is not suitable enough to handle the side effects (interview, November 30, 2015). This was the case for Lu Hong, a 46 year old woman interviewed at

Sunshine Homeland Clinic. Diagnosed with HIV and HCV in 2009, she attempted to take the treatment for HCV. However, after suffering from hair loss, fever, and a host of other symptoms, Lu stopped the treatment during her first round (interview, November 10, 2015). This scenario repeated multiple times throughout interview. Zhang Bing, a 43 year old male who was once an athlete, revealed that he attempted the treatment twice. The first time, he lasted for a month before he gave up due to the harmful effects. He completed the regimen on his second attempt but still was tested as positive (interview, November 10, 2015). This raises the question of whether or not it is worth it for patients to endure the harsh side effects without the assurance of a 100% success rate. This deters many patients, like Wan Xiaowei, from taking the regimen in the first place. Wan noted that he has chosen not to take the treatment because of the stories told by his friends about its side effects (interview, November 10, 2015).

In addition to side effects, the weak health of patients who also live with HIV contributes to the decision to take HCV treatment. Zhou Mi, a frail 28 year old woman, explained to me the state of her health. Zhou was diagnosed with both HCV and HIV in 2013. She immediately started taking treatment for HIV, but was forced to switch types because of the side effects she experienced. Today, she does not take treatment for HCV, but suffers from the side effects of HIV treatment, including headaches, hair loss, irritable skin, hearing problems, twitching of her hands, weight loss, blood in her throw up, and bad vision. As a result of the side effects associated with HIV treatment, HCV medicine is no longer a possibility (interview, November 11, 2015). When faced with the decision to take interferon and ribavirin treatment, the health of co-infected patients is much more fragile compared to non-co-infected patients. This threatens the likelihood of patients completing and even starting treatment. The treatment that currently is administered in China is harmful to a

patient's health and can be ineffective. There are major barriers patients must overcome to even obtain this medication, not to mention the barriers to obtain newly developed treatments.

Barriers to Accessing Treatment

There are numerous factors which serve as barriers to accessing hepatitis C treatment for patients, a majority of them stemming from structural problems. The Chinese government receives criticisms for shortfalls associated with administration of the health care system. Abstracts recorded from the 4th International Conference on Public Health among Greater Mekong Sub-Regional Countries presented research on disease prevalence, progress on current projects, and further gaps in understanding. Dr. Hongxiao Zhou analyzed shortcomings in the current health care system in his study "Thinking of Health System in China." His findings indicated that the weakest aspect of China's health care system is "disharmonious administrative management and poor evidence based policy making" (2012). These weaknesses translate to the number of people who do not have easy access to HCV treatment, like the many whom I interviewed. It appears that there is a disconnection between the administration level and the implementation level. Moreover, "poor evidence based policy making" indicates that not enough research is being done on public health issues to make sustainable solutions.

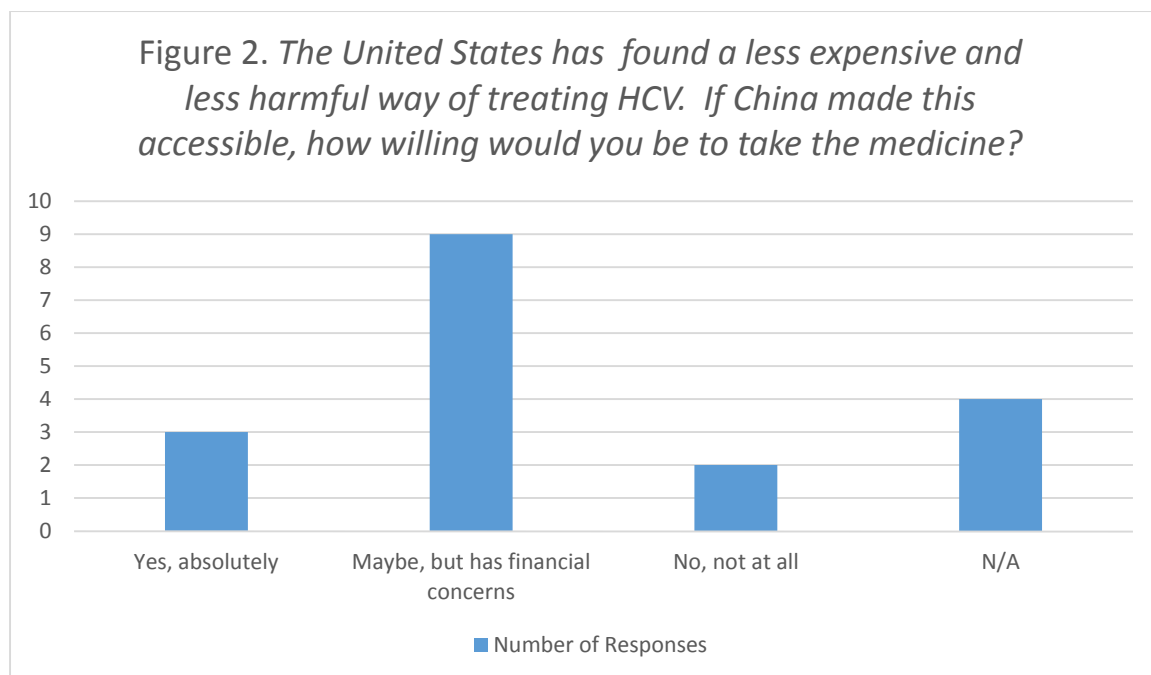
The Public Health Clinical Center in Chengdu serves as an example of effective system of public health. This top down system, funded by the government, serves the entire population of people infected with HIV and HCV in the capital city. Because of this, doctors are able to keep track of their patient's health status and create a regimen specific to the patient's health needs. Dr. He noted that the center's strategy has contributed to the 92% success rate in patients who take HCV medication. Furthermore, it proves why places outside of Chengdu without a similar system, like the rural area of Liangshan, have a

HIV/HCV co-infection rate among IDUs of 40% (interview, November 30, 2015). In sum, systematic strengthening is necessary to control and prevent HCV.

In addition to structural and administrative weaknesses, there are shortfalls that exist in the Chinese government's health care policy. According to Dr. Yang from the infectious disease hospital in Kunming, China's health care coverage falls into three categories: A, B and C. The health care policy ensures that category A diseases, which are life threatening, are entirely covered financially. HIV/AIDS falls under category A. Diseases categorized as level B are less life threatening so the government only subsidizes 80% of the costs. Hepatitis C falls under category B. Given that the cost for HCV treatment ranges from 10,000 – 70,000 RMB, 80% is still not suitable to cover patients, especially IDUs many of whom lack education and a steady income. If a patient does choose to utilize the insurance subsidization, they also must agree to the policy's requirements. For instance, the patient must live in the hospital for the first few months of treatment if he or she uses the medical insurance. In addition to the high cost of treatment, many are deterred because they do not want to live in the hospital for personal reasons. Dr. Yang did note however, that there are ways to apply to repeal this rule and set up a payment plan if costs are a concern (interview, November 25, 2015). Regardless of what medical insurance exists, finances are still the main concern for many patients.

An American pharmaceutical company, Gilead, has developed a treatment that is less harmful and more effective compared to the ribavirin and interferon combination. However, it has yet to be released to many low and middle-income countries, including China. Based on my interviews, it has already been proven that the harsh side effects of interferon and ribavirin stop patients from taking treatment and deter them from starting it. Gilead's Sovaldi and Harvoni treatment is the leading pharmaceutical drug in the United States to treat hepatitis C. It is unique because it contains sofosbuvir which inhibits the HCV virus from

spreading. The FDA recently approved that Harvoni is safe enough to treat patients co-infected with HIV. However, it comes at a high cost. In the US, one pill costs \$1,125 USD and ranges from \$64,000-\$189,000 for the course of the whole treatment (“Ledipasvir-Sofosbuvir”). If brought to China, the price would be too high for patients, especially IDUs, to afford (384,000 - 1,134,000 RMB). However, Gilead has begun to make agreements with Indian companies to manufacture a generic version of the drug. The list of countries which Gilead has approved the generic drug in includes 101 developing countries, but China is not one of them (“Chronic Hepatitis Treatment Expansion”, 2015). After personally inquiring with Gilead’s customer service in Asia about the treatment’s availability in China, I was informed that the medication is under “registration” and that the nearest place to access it is Hong Kong (email, Asia Med Info, 2015, Oct 16). The reason it is not available in China is under speculation. Some suspect that there is not enough social support being done while others speculate that the Chinese government is to blame. The WHO performed a systematic review of treatment outcomes in low and middle-income countries and uncovered the possible reason for this. The report stated, “Despite the benefits of treatment, there is a reluctance to making it more widely available in resource-limited settings because of fears that treatment success rates will be low and because treatment is complex, costly and produces side-effects. In addition, outcomes are often poor in patients coinfecting with human immunodeficiency virus (HIV)” (Harris et al, 2012). These aspects give reason as to why the Chinese government has not requested the generic medicine from Gilead. Regardless, 9 out of 14 people interviewed in my study said he or she would take this treatment, but under financial apprehensions (see figure 2). Finances remain to serve as the primary barrier to obtaining treatment, no matter what the treatment may be.



Another barrier to obtaining treatment is the Chinese system of law. It was found that in both Yuxi and Kunming, IDU clinical centers attract the police. Under Chinese law, intravenous drug use is punishable by arrest and jail sentence. Mr. Dai from the Harm Reduction Network in Yuxi mentioned that in the last few years the number of people who regularly attend the clinic had significantly decreased due to police deterrence. Three years ago the clinic helped around 500 people; however, today numbers have decreased to 200-300 people a year (interview, November 20, 2015). This serves as a large problem for people who need HIV and HCV services. As more people stop attending the clinic because they are afraid of being arrested for drug use, the less likely they will receive testing and treatment. The lives of drug users are also affected once he or she has been arrested. According to many patients, a record of unlawful activity greatly limits the opportunities of finding employment. This is the case for Liu Hong, a 35 year old male resident of Yuxi who was recently diagnosed with hepatitis C. Since his identification card indicates that he was arrested for drug use, employers refuse to hire him. Without a steady income, Liu cannot afford hepatitis C treatment regardless of the insurance policy (interview, November 20, 2015). Furthermore, IDUs like Liu are restricted when it comes to insurance. Dr. Yang Jie from the infectious

disease hospital in Kunming noted that drug users are disqualified from insurance for the first two years they are out of jail. He or she also cannot rejoin the system fully until being drug free for three years (interview, November 25, 2015). These tight restrictions make obtaining treatment extremely difficult, especially for the most vulnerable population of drug users who have been recently released from jail, who struggle from addiction, and who lack a steady income. In comparison to the protocol for hepatitis C treatment and drug users, there are no restrictions which prohibit a patient from receiving HIV treatment, even if he or she has a history of unlawful activity. In fact, the government mandates that HIV treatment is free and accessible for all. (Yang, interview, November 25, 2015).

The final barrier to treatment that I have noted throughout my studies is the social stigma that surrounds co-infected patients. Many drug users I interviewed voiced their fear of discrimination and demoralization for the actions associated with contracting HIV and HCV. Wan Xiaowei, a 40 year old man interviewed at Sunshine Homeland Center, admitted that he has not told his parents about his health because he fears being rejected (interview, November 10, 2015). Many IDUs like Wan Xiaowei chose not to tell loved ones despite the possibility that their family could financially assist them to cover treatment costs. Another barrier associated with stigma occurs within the medical world as well. Zhou Mi, a co-infected woman whose health was extremely poor, shared that a doctor denied her medicine to treat the harmful side effects of HIV because she was co-infected with HIV and HCV (interview, November 10, 2015). It seems that the stigma is heightened around co-infected patients. The saddening story told by Yang Li Kun exemplifies the debilitating strength of stigma. Diagnosed with HIV and hepatitis C in 2001, Yang's health has deteriorated to the point where he can no longer work. Furthermore, he does not take treatment for either disease. Yang lives under a shadow of stigma and discrimination. His mother and father are faced with the financial obligation of caring for their son who is unable to contribute to familial

income. His poor health should make him eligible for financial insurance from the government for 200-300 RMB a month, but any local official would deny him of this because they know he is a drug user. His mother broke into tears when sharing this information because of the financial stress of sustaining their family and caring for their dying son on the 20-30 RMB a day. Families like Yang's are unable to afford basic living costs, let alone the cost of hepatitis C treatment for their son (interview, November 20, 2015). Yang's story not only exposes that stigma prohibits co-infected patients from financial opportunities, but more importantly it gives reason why treatment for HCV must be free and accessible.

Coping Methods and Alternative Treatments

Once a patient accepts that he or she is unable to take the treatment, they must face the emotional reality that their health will progressively deteriorate. They have two choices, give up hope for living or cope with their diseases. I investigated this question during my interviews with IDUs both in Yuxi and Kunming. The results were mixed. Many individuals like Zhou Mi, a 28 year old woman who contracted both HCV and HIV from her husband, had very low spirits as a result of the harsh side effects of HIV medicine (interview, November 10, 2015). Zhang Ming bluntly stated that after he was diagnosed with both HIV and HCV, he fell into depression and contemplated suicide often (interview, November 10, 2015). However, many co-infected patients have learned to cope with their situation. Yen Liwei, a 48 year old man who is HIV positive, utilizes Sunshine Homeland's services for emotional support. He praised Sunshine Homeland for providing an open environment and activities which allow people to feel comfortable and consoled during hard times (interview, November 11, 2015). Sunshine Homeland is one of many of centers in Kunming which provide services and outreach for IDUs and patients living with HIV. Their services include methadone treatment for drug addiction, HIV treatment distribution, educational services to prevent the spread of HIV and HCV, and community support activities. By law, those who

take antiretroviral medication must make daily trips to treatment distribution centers, like Sunshine, to be treated. This allows patients the chance to build relationships with other HIV and/or HCV infected patients so that a support system can be built. For many, the support system drastically improves their outlook on life. Zhang Xiao Rong, previously mentioned for being more concerned for her HCV infection than for HIV, shared that her depression subsided after she started attending Sunshine Homeland. Furthermore, she wished she had started coming to Sunshine Homeland earlier (interview, November 11, 2015). Not only does Sunshine Homeland Center provide treatment, but more importantly the center helps people like Luo Shao Wen cope with the emotional stress of the disease. Luo and his wife, Guo Zhong Ping, have a long painful history associated with their infections. Both are co-infected with HIV and HCV and although they support one another, Luo must cope with that fact his wife's health is failing faster than his. She takes treatment for HIV but does not receive treatment for HCV. Doctors have confirmed that she has a high virus level in her liver, but her health too weak to take the harsh HCV treatment. Despite her failing health, the couple attributes their emotional strength to Sunshine Homeland's support and services (interview, November 11, 2015).

Without access to treatment, co-infected patients find emotional reprieve from communal support. In addition, I found that Traditional Chinese Medicine (TCM) serves as an alternative to the costly Western Medicine for many co-infected patients. Out of the 18 interviewees, four of them mentioned that they took some form of TCM to protect their liver, offset the side effects of HCV or HIV treatment, and improve their overall health. With its holistic approach to health, TCM is a science that the Chinese have practiced for over 2,000 years. The ideological foundation rests upon the balance of Yin and Yang. The practice acknowledges that we as humans are not disconnected to nature, but rather are an integral part of nature. With this idea, TCM takes advantage of natural resources to realign the

balance of Yin and Yang and thus fix bodily ailments. Unlike popular belief among many Westerns, this Western Medicine alternative is widespread throughout the country and is deemed a legitimate form of medicine. While there are many health benefits to TCM, it is also worth noting that TCM treatment and medication is completely covered by insurance (Dr. Zhang, interview, November 24, 2015). It is no wonder so many HIV and HCV patients seek aid in Traditional Chinese Medicine.

To investigate more about this alternative method of treatment, I interviewed a TCM Doctor from the Traditional Chinese Medicine College and Hospital in Kunming. Dr. Zhao, who specializes in the combination of Western Medicine and TCM for diagnosis and treatment, spoke with me regarding the use of TCM for treating hepatitis C. He eagerly explained to me the ideology behind the treatment he typically prescribes for patients. Both HIV and HCV are infectious disease contracted via blood. Ideologically speaking, treatment must involve outside aid, such as herbs and plants, to fight the foreign virus that also originated from “the outside.” Herbs and plants aid the body in self-regulating virus levels and promote healthy organ function. Dr. Zhao noted that there is not one treatment regimen for hepatitis C, nor is there one for HIV. Whether the patient has HIV, hepatitis A, hepatitis B or hepatitis C, treatment is catered towards the patient’s virus level, overall health, and age. A typical regiment Dr. Zhao recommended is known as the “white tiger” because of his powerful effects. The combination includes Indigo herb, Doufu, and Chrysanthemum. Because the virus creates high temperatures in the body, Clean Heat, or heat that is used to balance out bad heat caused by the virus, is the primary method to decrease virus levels. The goal is for the patient to return to a homeostatic state. The doctor noted there are over 900 herbs and supplements that serve as Clean Heat. Indigo is the Clean Heat of choice the doctor prescribes to treat hepatitis C. Doufu is the second treatment among the three. This fermented soybean vegetable protein, called “tofu” in English, provides another form of

Clean Heat as well as supplemental nutrition. The third leg of the “white tiger” treatment includes Chrysanthemum, a Clean Heat that cleanses the body. Along with the prescribed treatment combination, the doctor also recommends a combination of supplements which provides the body with energy to maximize healing power, such as Ginkoes, CoptisChinensis, and water buffalo horn powder. Finally, the doctor noted that repeated acupuncture sessions increases the body’s natural antibody count to reduce the virus level in the liver and chances of developing liver cancer or cirrhosis (interview, November 24, 2015).

Speaking in terms of practicality, TCM treatment is a suitable alternative to Western Medicine. For one, the health of many patients increases drastically. Dr. Zhao noted that in his 30 years of TCM practice, he has experienced patients who are completely free of the hepatitis C virus after taking the regimen. There is also evidence that points to reduced virus level in the liver which allows patients to live longer lives. In addition to the proven health benefits, TCM treatment is comparatively more affordable. Dr. Zhao proudly stated that aside from everyday items such as Doufu, 100% of the treatment costs are covered by insurance (interview, November 24, 2015). This is a significant attribute for a majority of people living with HCV because many IDUs often do not have a steady income. Furthermore, it is worth noting that government granted insurance only covers 80% of HCV treatment. Without easy and affordable access to HCV treatment, Traditional Chinese Medicine serves as a practical alternative for many IDUs. It is among many ways patients with HIV and/or HCV cope with their failing health, when medical treatment is not an option.

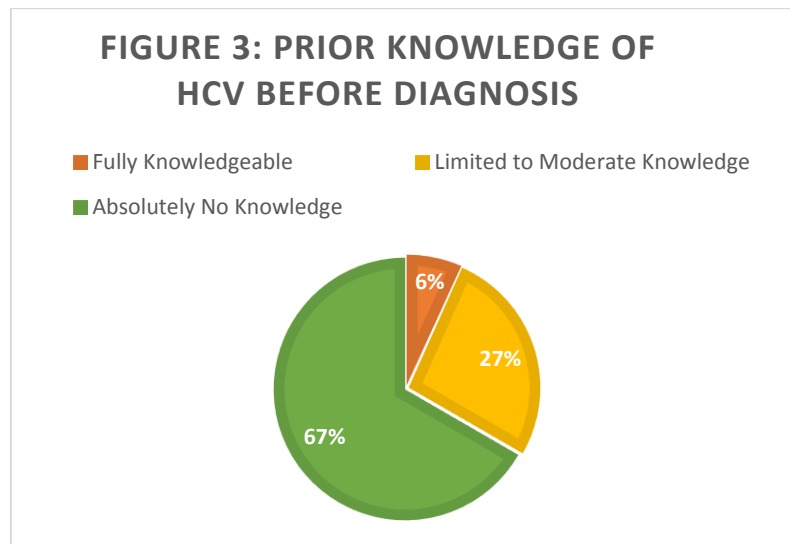
Contrasting HIV and HCV Educational Awareness and Health Care Initiatives

One must look through the lens of the HIV health care policy in China to better understand the gaps in prevention and treatment efforts for HCV. After the spread of HIV reached epidemic levels in the 1990’s, the government launched a three year program in 2005 nicknamed the “people’s war” against HIV/AIDS. The goal was to utilize sectors at all levels

to prevent and control the spread of HIV. However, after a semi-successful three year period, an improved long term program was established to fill the gaps that the short term project failed to address. Partnered with the USAID's Health Policy Initiative in the Greater Mekong Region and China project, the Yunnan Provincial Aids Bureau focused on systematic strengthening in Yunnan, where HIV rates towered over the rates of other provinces. The long term project encompassed system strengthening at all levels, stigma awareness, and private and public partnership in order to create a more harmonious system. In addition, the nation-wide system known as the "The Four Frees and One Care Policy" was implemented and continues to be used today. The "Four Frees" which the program involves is free HIV testing, free antiretroviral drugs for patients infected with HIV, free medication for pregnant women infected with HIV, and free education for orphans living with HIV. All of this, in addition to financial assistance for low-income families with a family member living with HIV, falls under the "One Care Policy" ("Moving Towards", 2009). Today, HIV clinics are accessible throughout China and administer HIV treatment. Sunshine Homeland Center is one example. Thanks to the nationwide effort to fight the People's War on HIV, more people are taking treatment for HIV. According to AVERTing HIV and AIDS, the number of people on antiretroviral treatment in China has nearly doubled, from 126,488 in 2011 to 227,489 in 2013 ("HIV and AIDS in China", 2013). The rapid action China took against the war on AIDS has been internationally praised and the program is growing as each year total HIV spending is increasing. In 2010 HIV spending in China was \$580,000,000 USD then rose to \$630,000,000 USD in 2012 ("HIV Spending", 2014).

The capability and capacity for a nationwide war against hepatitis C is possible given the success of the AIDS program. However, it is not being done. Thus far, no national program has been initiated to specifically target HCV prevention and treatment. In fact, interviews with people living HCV revealed that there is a huge lack of educational

awareness surrounding HCV. When asked if they had any prior knowledge of HCV before diagnoses, only one person knew fully about the disease(6%), four had limited to moderate knowledge (27%), and a staggering 10 people had absolutely no knowledge (67%) (Figure 3). These results indicate that lack of educational awareness is common and gives reason to why there is a rising problem of HCV in China.



Another study conducted by a team from Population Services International (PSI) investigated the knowledge of HCV among IDUs in Southwest China. The information consensus was taken from a pool of 1,037 adult IDUs participants. The results indicated that 88.3% had prior knowledge of HCV, however very few knew specifics about the disease itself. For example, only 19% of IDUs knew that sharing needles/syringes could transmit HCV. PSI concluded from the results that there is “a need for integrated inexpensive or subsidized services for vaccination, and treatment/care...to help reduce the high burden of morbidity and mortality associated with infectious diseases among PWID [people who inject drugs] in China” (Wang et al, 2012). This information, combined with the information I gathered from interviews, reveals that not enough educational awareness is being implemented in China surrounding HCV.

Further information given by Mr. Dai from the Harm Reduction Center in Yuxi echoed that the current efforts being made are not enough. As previously mentioned, Yuxi has a high number of IDUs. This, along with the high number of people dying of hepatitis C, has gotten the attention of NGOs and government health entities. In the last two years alone, Mr. Dai has noted a decrease in the number of people being diagnosed with HCV. He accredits this to the new educational awareness measures that are being put in place by NGOs and public health organizations (interview, November 20, 2015). However, a fellow colleague at the center and a grassroots member of Yundi, Zhang Xiaomin admitted that NGOs come into the center to acquire statistical information and record observation, but they do not provide anything which has yet to make any change (interview, November 20, 2015). Mr. Dai, given his experience at the center and as a person who is living with hepatitis C himself, proposed a solution he argued was necessary to combat HCV. He proposed the government build a system like the one built for HIV, one that entails widely accessible HIV clinics and free treatment for everyone (interview, November 20, 2015). However, given the current circumstances, a system like the one proposed by Mr. Dai is still far from being achieved.

Conclusion:

China has entered an era where it has the resources and leadership to better improve its health care system; however, the country must do so before diseases spread quicker than can be controlled. Already, China is in the top three countries which carry the weight of the world's population living with hepatitis C. On the one hand, the current health care system provides Chinese citizens with medicine, a majority of the price subsidized for. But on the other hand, it is not reaching the citizens that need it the most. Therein lies the problem: the treatment has been developed in the United States, and China has the capacity to extend its reach to all citizens like it did with the movement against HIV, but there is a gap between the administrator and the patient. Dr. Yang stated that there is typically a success rate of 95% among her patients who take hepatitis C treatment. She even noted that patients who hesitate for financial reasons usually agree after creating a payment plan (interview, November 25, 2015). Furthermore, Dr. He from Chengdu also proudly stated that there was a 92% success rate among patients who attended the clinic for HCV treatment (interview, November 30, 2015). Neither doctor recognized that there were weaknesses that exist in the current system. However, interviews with the 18 IDUs proved otherwise. Out of the 14 individuals who were infected with HCV, none had successfully completed the hepatitis C regimen. The three that had attempted the treatment either stopped halfway because of the harsh side effects or had completed the treatment but still tested positive. The remaining 10 IDUs have never taken HCV treatment mainly due to financial hesitations. Because these two discoveries harshly conflict, it is of highest importance for government and private entities to understand the gap between what doctors experience to what is true among the IDU community. Intravenous drug users are one of the most vulnerable populations to be infected with HCV, but they are also the most likely to lack economic opportunities. Thus, hepatitis C treatment must be

altered in two ways. For one, the generic version of Gilead's sofosbuvir must be allowed in China. Secondly, treatment must be completely subsidized by China's health care.

The barriers which currently exist can only be categorized as unjust. Intravenous drug users, many of whom are predisposed to their circumstances given their economic instability and external influences, face stigma as the largest injustice against them. This injustice prevents them from being employed, affording treatment, and creating a stable life. Furthermore, efforts to lessen and reverse stigma have not been executed like they have been for patients living with HIV. Patients with HIV can receive free treatment regardless of a history of unlawful activity, whereas patients with a record will not qualify for insurance to cover 80% of the cost associated with HCV treatment. Another injustice is the fact that pharmaceutical companies, like Gilead, do not make their patents available globally. This stems from profit oriented motives. As a result of these injustices, many are faced with how to cope with stigma and disease. Reprieve is often found in community organization like Sunshine Homeland Center which provides support in a setting where patients share many of the same difficulties. In addition, patients alike turn to Traditional Chinese Medicine as an alternative to the costly and ineffective treatment. These measures have provided hope for many who are faced with life threatening diseases.

The problem surrounding hepatitis C in China was looked through the lens of HIV, thus the solution must do the same. Mr. Dai from the Harm Reduction Network in Yuxi provided the most logical solution to the current problem. He proposed that in order to prevent HCV from reaching epidemic levels, a similar movement like the one enacted for HIV must be implemented. A movement of the sort would call for HCV specific clinics accessible throughout the country, free treatment to all, and educational prevention efforts. It is my hope that this research will raise awareness about the gaps in knowledge and efforts surrounding hepatitis C and create a sense of urgency to fill them. The global HIV pandemic

killed millions of people in the ten year period before the fight to provide treatment for all was won. Let us not allow history to repeat itself.

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Appendices:

Appendix A: Interview Questions for Intravenous Drug Users in Kunming and Yuxi

All...

1. Background - age, job, educational background, family?
2. What are they infected with?
3. How did you hear about Sunshine?

Drug Users only...

4. When did you start using drugs? How old were you? How old are you now?
5. Do you share needles?
6. Do you use condoms during sex?
7. Are you aware of how HIV is contracted? What do you know about Hepatitis C?
8. Do you get tested regularly?
9. Are you concerned with your health? Do you take the necessary precautions to prevent getting HIV or HEP C?

HIV Patients only,

10. When were you diagnosed with HIV?
11. Before you were diagnosed, were you aware of HIV?
12. What do you know about Hepatitis C? How do you know what you know?
13. Do you take necessary precaution to avoid contracting HCV?
14. How is your physical and emotional health? What is your outlook looking forward into the future?

Co-infected Patients

15. Before you were diagnosed, what did you know about HIV and HCV?
16. How is your general emotional and physical health? What is your outlook looking forward into the future? What is your biggest health concern?

17. The United States has found a less expensive and less harmful way of treating HCV. If China made this accessible, how willing would you be to take the medicine?
18. What affects your life more, HIV or HCV? Which one is your biggest concern?
19. Does your family support you?